

Breaking the expertise barrier: understanding activist strategies in science and technology policy domains

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This article develops a classificatory framework for analyzing advocacy group strategy in S&T policy domains — an area of increasing citizen activism since the 1960s. In such domains, activists may be locked out by what I call the ‘expertise barrier’, which blocks those lacking specialized knowledge from full participation. This article argues that activists’ strategies to break through the expertise barrier can be classified into four categories: deploying established expertise, introducing new kinds of facts, introducing new policy-making logics, and attacking bureaucratic rules. It suggests further that focusing research on these four categories can facilitate hypothesis generation and future avenues of inquiry, including comparison among advocacy challenges in diverse technical domains. To illustrate this framework, I present examples from activism in two areas: breast cancer research and patents on life forms.

FOR THE PAST 40 YEARS, democratic politics have experienced a significant increase in organized challenges to policy domains that are highly scientific and technical in character (Bauer, 1997; Hess, 2007; Corburn, 2005; Frickel and Moore, 2006; Nelkin, 1984). This activism involves members of the public, such as patients, consumers, and citizens, who are unhappy with policies related to science and technology and have therefore

begun to demand a voice in their development. In launching such challenges, these individuals and groups often confront what I call the ‘expertise barrier’: the formal and informal rules of a science and technology policy-making domain which make it difficult for those without technical expertise to engage as equals. This article introduces a framework to facilitate analysis of the strategies that activists use to penetrate such ‘expertise barriers’, identifying four categories of action:

1. Deploying established expertise;
2. Introducing new kinds of facts;
3. Introducing new policy-making logics; and
4. Attacking bureaucratic rules.

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This framework aims to draw together insights from the growing body of scholarship on activism in S&T policy domains (see, for example: Epstein, 1996; Jasper and Poulson, 1995; Klawiter, 2008; Frickel *et al.*, forthcoming; Brown *et al.*, 2004) and provide points of comparison. This will help us develop hypotheses about which strategies for penetrating expertise barriers are most likely to be used and to be successful, under various circumstances.

The next section discusses this article’s theoretical foundations and describes the classificatory

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framework outlined above in some detail. I then provide a brief background on the two cases used to illustrate the utility of the framework: breast cancer and life-form patent¹ activism. The article then uses examples from these cases to further define the framework and demonstrate its use. What strategies do activists use to break expertise barriers? How do breast cancer and patent activists employ these strategies in practice? Do advocates typically use strategies from all of these four categories and do they tend to follow some sort of progression? The article concludes with reflections on the benefits of a comparative framework and discussion of how this approach can facilitate future research, including assessments of success and failure of activism in S&T policy domains.

Breaking the expertise barrier: classifying activist strategies

Scholars of the policy process have demonstrated that issue-focused policy domains — which can be defined as including the rhetoric, actors, and institutions engaged in developing, debating, and implementing policies on a particular issue — are relatively stable (Baumgartner and Jones, 1991, 1993; Jenkins-Smith and Sabatier, 1994; Sabatier, 1988). In these domains, policies rarely shift dramatically, and usually involve the same players, often locked in similar conflicts, over significant periods of time. Participants in a policy domain often share a basic understanding of the facts and issues under debate and the relevant legal and regulatory frameworks, and sometimes even possess similar backgrounds.

Consider, for example, the biomedical research policy domain in the United States. The institutions engaged in the domain include relevant Congressional committees, the NIH and other science funding agencies, institutional review boards, and sometimes even state legislatures and state funding agencies. Non-institutional actors include scientific and medical organizations, individual scientists and physicians, biotechnology and pharmaceutical companies, universities, and patient advocacy groups. The frames that shape the policy process usually focus on finding cures and scientific freedom (Dresser, 1999; Pavitt, 1999).

Outsiders usually attempt to gain influence in a policy domain by opening up the scope of discussion in ways that destabilize the position of the traditional players (Schattschneider, 1960). They may try to create a frame that they believe is powerful enough to attract public support to their cause, or seek out coalition partners or venues that are open enough to allow them to broaden the policy debate (Baumgartner and Jones, 1993; Pralle, 2006; Snow and Benford, 1988.) They face difficult challenges, however, as political institutions are often closed and even hostile to their participation, and insiders who might make good coalition partners do not want to jeopardize their power (McAdam *et al.*, 1996). Scholars have long been interested in the strategies that outsider activists use to penetrate the institutions and dominant frames of these domains (McAdam *et al.*, 2001; Tilly and Tarrow, 2006); here, I focus specifically on how activists confront the expertise barrier created by the shared knowledge of the domain. This expertise barrier limits (and sometimes keeps out entirely) participation from individuals and groups that lack this knowledge, while also limiting the kinds of discussions (and particularly the types of critique) that occur.

While many domains may have high expertise barriers due to the technical nature of discussion and the backgrounds of the players who usually participate,² this article focuses on S&T policy domains. The high expertise barriers of these domains are difficult for activists to confront for multiple reasons. The traditional participants are usually highly trained and the topics are difficult for non-experts to comprehend. Not only do stakeholders often have high levels of education and professional training, but also highly credentialed experts play particularly important roles, sitting on advisory committees that decide which drugs to approve, for example, or which chemicals are safe for public use (Jasanoff, 1990b; Hilgartner, 2000.) Bureaucracies in these domains employ personnel with advanced degrees to make decisions on the basis of complex legal rules and scientific evidence. In fact, even when they occur in legislatures or the courts, policy discussions are usually extremely technical. Scholars have become increasingly interested in the role experts play in these domains and the implications for democratic legitimacy (Brown, 2009; Guston, 1999; Hoppe, 1999, 2009; Maasen and Weingart, 2005).

Members of the public have had difficulty engaging with these domains, because the technical concepts and language seem difficult to master and because the imbalance of knowledge between insiders and outsiders appears considerable. Although in recent years there have been numerous proposals to incorporate citizen participation in S&T policy (Anderson and Jaeger, 1999; Durant, 1999; Ferretti and Pavone, 2009; Fischer, 1999; Guston and Sarewitz, 2002; Rayner, 2003), they have had limited impact — especially in the USA — as insiders often argue that the average person operates at a

knowledge ‘deficit’ and cannot properly comprehend the complex issues under discussion (Wynne, 2006.)

The framework developed here is based on the results of both my own empirical research³ and a growing body of scholarship analyzing activism in the arenas of science, technology, environment, and health. Brown *et al.* (2004), for example, have examined ‘embodied health movements’, which operate in the highly technical domains related to ameliorating human disease. These groups draw together patients who share an experience of suffering from a particular disease to engage the S&T policy establishment. McCormick (2007) has examined ‘democratizing science’ movements, which ‘contest, reframe, and engage’ the production of official scientific research to achieve their goals. Others have unraveled elements of activists’ strategies through rich case studies of individual movements (see, for example: Epstein, 1996; Brown *et al.*, 2000; Brown and Gibbs, 2007; Klawiter, 2008; Kleinman and Kinchy, 2007; Silverman and Brosco, 2007). Generally speaking, however, these analyses are domain-specific, focusing on health social movements, for example, or environmental activism. Given the rise of both advocacy group engagement and the scholarly attention to it, my goal here is to provide a framework designed to facilitate classification, comparison, and understanding of activists’ efforts to penetrate expertise barriers, as a step towards understanding the conditions for their success and failure.

The four categories that make up the framework proposed here are intended to capture most of the strategies used to break expertise barriers. After describing the four categories, I use the breast cancer and life-form patent cases to provide illustrative examples and to demonstrate how the framework can help develop hypotheses about the use and success of advocacy strategies in highly technical domains.

1. Deploying established expertise

Many case studies have demonstrated that when challengers engage with scientific, technological, or medical policy domains, they usually try to assert the legitimacy of their participation by demonstrating to insiders their mastery over the highly technical

topics already under discussion (Brown *et al.*, 2006; Epstein, 1996; Dickersin *et al.*, 2001). Parents challenging the system of compulsory child vaccination against the measles, mumps, and rubella (MMR) vaccine in Britain, for example, both enlisted the help of sympathetic scientists and physicians and learned the language and concepts of clinical science and epidemiology themselves (Leach, 2005, 2007). This strategy allowed them to interrogate the assumptions of expert insiders at a detailed level, and ultimately achieve more public attention to their concerns. Although all outsiders must learn the language of the policy domain they are targeting, this challenge is often particularly difficult in domains that engage in S&T policy-making due to their technical and specialized nature.

2. Introducing new kinds of facts

Not only do activists try to establish mastery over the evidence already used in a policy domain, but also they attempt to introduce new kinds of facts that insiders have not traditionally considered (and, sometimes, do not even consider to be ‘facts’). This strategy allows activists to claim special expertise over the new evidence they introduce, which can strengthen their claims for standing within the domain (Caron-Flinterman *et al.*, 2005; Silverman and Brosco, 2007). In some environmental areas, for example, individuals and groups have even tried to influence the policy process by doing ‘citizen science’ (Irwin, 1995), generating their own technical evidence. Ottinger (2010) has demonstrated how citizens concerned about air quality in Louisiana monitored toxicity levels by capturing air in buckets and then sending the resulting data to decision-makers. In these efforts, activists play on the presumption that policy decisions are supposed to be evidence-based. How can insiders ignore any kind of evidence? they ask. Shouldn’t good public policy be based on as much evidence as possible? In asking these questions, they often suggest that the policy-making process can only be truly adequate and evidence-based if a comprehensive approach is taken to fact-gathering and their new evidence is included — which makes them legitimate experts in the domain as well.

3. Introducing new policy-making logics

Activists sometimes try to change what we might call the policy-making logic in a particular domain. Policy-making logics drive evidentiary expectations, influencing how evidence and expertise are valued and balanced to make policy decisions (Feldman *et al.*, 2006; Hilgartner, 2009.) The USA and European Union, for example, have adopted rather different logics for regulating genetically modified organisms (Jasanoff, 2007; Levidow *et al.*, 2005; Tickner and Wright, 2003). In the EU, the regulatory logic follows the ‘precautionary

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principle', in which the genetically modified organism is assumed to be unsafe for widespread consumption until the producer generates evidence demonstrating safety. By contrast, US policy assumes that genetically modified organisms are substantially equivalent to their non-genetically modified counterparts. The evidentiary burden is placed on challengers to prove that a particular genetically modified organism is unsafe.

Actors in highly technical policy domains often try to gain influence by challenging how knowledge is framed and contextualized (Gottweis, 1998; Hajer, 1995; Schön and Rein, 1995); Keller (2009) argues that scientists involved in environmental policy debates introduce 'science narratives' to advance their policy agendas. Outsider activists adopt a similar strategy, trying to break the expertise barrier by identifying problems in the prevailing policy logic and introducing a new approach. Their new proposed logic typically emphasizes the unique expertise they bring to the discussion. As they do this, they are attempting to create a major conceptual shift, not simply questioning evidence and expertise. They seek a significant reworking of how facts are incorporated into the policy process.

4. *Attacking bureaucratic rules*

Outsider activists sometimes try to penetrate the expertise barrier of S&T policy domains by arguing that the formal and informal rules of bureaucratic decision-making are inappropriate and perhaps even detrimental to the public interest (Johnson and Fee, 1994; Ingram and Ingram, 2005). This can be a particularly powerful line of attack because bureaucracies play central roles in S&T policy domains, and have traditionally established and maintained their political legitimacy by emphasizing the rationality of their technical decision-making processes (Ezrahi, 1990; Porter, 1996; Jasanoff, 1990b.) Activists may attack bureaucratic rules by not only identifying the problems or bias in individual decisions, but also arguing that decision-making that appears detached and objective masks systematic biases that do not necessarily serve the public interest. AIDS activists, for example, accused the FDA of having drug approval processes that focused on scientific priorities — to produce standardized, generalizable results according to an evidentiary 'gold standard' — rather than on meeting patient needs (Epstein, 1996). Patients were dying, they cried, because of FDA's rules. In articulating these challenges, activists often use the language of democracy: in a democratic society, they ask, is the current approach to decision-making in this bureaucracy appropriate? Is it in the public interest?

There is some evidence to suggest that expertise barriers, and advocacy efforts to break them, may differ across countries (Jasanoff, 2005; Jasanoff, 1990a; Halfman, 2005; Leach, 2007; Lentsch and Weingart, 2009). Identifying cross-national differences among

these barriers, particularly by comparing similar policy domains, is an important area for future study. To simplify discussion of the classification framework provided here, however, the remainder of this article focuses only on breast cancer and life-form patent advocacy strategies in one country, the United States.

Breast cancer and patent activism: two illustrative examples

To illustrate how the framework described above can organize research and provide a valid comparative logic, I provide examples from the histories of breast cancer and life-form patent activism. At first glance, these two types of activists might appear rather different. Breast cancer activism is an iconic example (Brown and Gibbs, 2007; Klawiter, 2008; Parthasarathy, 2007) of disease-based advocacy, while activism against patents on life forms, which is also stimulating increasing scholarly and media attention (Dutfield, 2004; Karanovic, 2007; Gold and Caulfield, 2002; Schwartz, 2009), involves a diverse set of actors.

Despite these differences, they have important similarities that are particularly relevant to this analysis. Both emerged in the late 20th century to challenge the 'expertise barriers' of highly technical policy domains: breast cancer activists began by questioning the allocation of research funding, while critics of patenting life forms attacked the development and implementation of patentability rules. Also, when they began their challenges, both sets of activists were new to their respective policy domains, and insiders did not see them as legitimate participants.

Breast cancer sufferers and their families began to target national policies in the early 1990s, after the previous successes of the women's health and AIDS movements (Lerner, 2003; Morgen, 2002). The National Breast Cancer Coalition (NBCC) led this effort, which included women's rights activists and leaders of breast cancer support groups across the country, to fight for better disease prevention techniques and a cure for the disease (Stabiner, 1998). Frustrated that women contracted and died of breast cancer at very high rates, NBCC argued initially that the federal government was not spending enough money to study a disease that had become an 'epidemic' among women. In 1991, it asked Congress to increase funding for breast cancer research by US\$300 million per year (yearly funding in the previous fiscal year was approximately US\$100 million).

At that time, the National Cancer Institute (NCI), part of the National Institutes of Health (NIH), was the government agency primarily responsible for funding breast cancer research. The NCI's leadership, the researchers who received funding from the NCI, and the outside scholarly experts who made

funding decisions worried about the emergence of these activists in discussions about research policy. Even though they would likely get more funding, both government officials and scientists fought the involvement of activists by suggesting that they would spoil the rational processes that had been developed to determine and distribute research funding. One prominent cancer scientist argued,

The most interesting and innovative ideas that have revolutionized biomedical research have by and large come from scientists ... and not from bureaucrats — be they from government or advocate groups. (Erikson, 1995)

Activists, however, were not deterred, and initiated a multi-year strategy to change breast cancer research funding policy in the USA.

Activist challenges to patents on life forms began in the late 1970s. Jeremy Rifkin, who had become as a major critic of biotechnology by this time, organized a coalition of groups to write an *amicus curiae* [friend of the court] brief to the US Supreme Court in the *Diamond v. Chakrabarty* case (People's Business Commission, 1979). The *Chakrabarty* case focused on the patentability of a genetically engineered micro-organism manufactured by General Electric; the court would decide whether the US Patent and Trademark Office (PTO) could issue patents on living organisms. PTO had initially rejected the patent because it had never before encountered such claims, hoping that the court could provide it with clarification. The court ultimately ignored the activists' brief — the only one against the patent — and decided (5–4) to allow patents on life forms (*Diamond v. Chakrabarty*, 1980).

The ruling did not deter challengers, however. Rather, as the PTO began to grant patents on more complex life forms, including higher-order organisms and human genes, challengers began a more intensive period of mobilization to fight the practice. They brought together environmental groups, animal rights organizations, bioethicists, religious leaders, and others who had concerns about the increasing privatization of 'life itself' (Lewin, 1996; People's Biotechnology Commission, 1979; US House of Representatives, 1988).

Like breast cancer activists in the biomedical research policy domain, opponents of patents on life forms seemed like alien figures in the patent policy domain, in which the players had historically been companies, universities, patent lawyers, and independent inventors. Not surprisingly, then, insiders responded to these challengers quite similarly to how insiders in the research policy domain had responded to breast cancer activists. They suggested that activists misunderstood the nature and scope of patent policy, and that the issues that they raised were inappropriate. In response to the activist brief in the *Chakrabarty* case, for example, the American Patent Law Association stated,

The Patent and Trademark Office well knows that its function is to *examine* inventions presented to it for compliance with the patent statutes, not to *regulate* hazardous research. [emphasis in original] (American Patent Law Association, 1980)

Insiders also noted that serious consideration of the challengers' arguments could have very negative effects for the future of innovation and national economic growth (Genentech, 1979).

In sum, both breast cancer and patent activists faced similar challenges as they tried to break into S&T policy domains. Insiders argued that activists lacked the knowledge to participate, raised irrelevant concerns, and threatened the objective nature of decision-making. Through the remainder of this analysis, we will see that activists also structured their responses to these barriers in broadly similar ways.

Deploying established expertise

Breast cancer advocacy groups tried to deploy established expertise in at least two ways: by taking advantage of well-established insiders who were sympathetic to their cause, and by creating a formal science-training program for activists. Susan Love, a breast surgeon at University of California–Los Angeles, who had published the best-selling *Dr. Susan Love's Breast Book* (Love, 1990) and co-founded NBCC, for example, played an important translational role (Stabiner, 1998). She had not only the professional credentials to be respected by insiders in the research policy domain, but also the demonstrated commitment to empowering women to fight the disease. Thus, in the early 1990s, when she was appointed to various national cancer policy committees, including President Clinton's National Cancer Advisory Board, she could make the case to her colleagues why it was important for breast cancer activists to participate in the policy process, and they were likely at least to listen. Simultaneously, she could teach activists about the technical language and concepts used in the domain, and about its often tacit and informal rules of engagement.

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NBCC did not rely simply on sympathetic insiders, however. It developed a formalized mechanism to teach its activists language and concepts related to breast cancer S&T, arguing that patients needed to be 'well-prepared, knowledgeable, and confident' to be respected by insiders and truly influence the process (NBCC, 1998). NBCC established this science-training program in 1995 and called it Project LEAD. Scientists and physicians from across the country (including Susan Love) spent a week multiple times a year teaching activists the basic biology of cancer, concepts in epidemiology, and how to critically appraise scientific literature. An NBCC brochure described the purpose of the program by noting, 'We believe that activists must be knowledgeable and articulate in order to be effective advocates' (NBCC, 1998). The scientists and government officials who had traditionally populated the breast cancer research policy domain had responded negatively to activists' initial demands because they argued that these laypersons were too unqualified and politically driven; now, however, these insiders had to deal with challengers who had not only the experience of suffering from breast cancer, but also the tools to engage in detailed scientific discussion.

Challengers to the patenting of life forms also established their expertise by taking advantage of sympathetic insiders. Unlike breast cancer activists, however, patent challengers did not have the advantage of a high-profile insider like Susan Love, who could help them. Instead, they relied on lesser-known figures — usually patent lawyers — who were sympathetic and willing to lend their services on a case-by-case basis.

Consider, for example, a patent challenge mounted by the Foundation for Taxpayer and Consumer Rights (FTCR), a consumer-rights organization based in California. In 2006, FTCR became concerned that the PTO had granted patents on human embryonic stem cells (hESCs) to the Wisconsin Alumni Research Foundation (WARF) (based on the work of James Thomson, a cell biologist at the University of Wisconsin.) Patents on hESCs, FTCR worried, would slow scientific research (by preventing researchers from working freely) and increase the costs of any medical technologies that were eventually developed (because WARF would expect royalties) (FTCR representative, personal interview, 2009).

Because it had no expertise in patent law or policy, FTCR worked with Daniel Ravicher, a patent lawyer who had recently established the Public Patent Foundation, an organization focused on 'representing the public's interests in the patent system' (Public Patent Foundation, 2009.) Ravicher concluded that the best way to challenge the patents would be to ask PTO to 're-examine' them (FTCR representative, personal interview, 2009). However, this approach required both Ravicher and FTCR to re-interpret their concerns to fit the rules of the process. The PTO would not grant patent re-examination

because of the possible negative implications for research or health care; they would have to argue that the patents were invalid because the inventions were not 'novel' (United States Patent and Trademark Office, 2008). Because Ravicher understood the language and concepts of the domain, he could transform FTCR's concerns into an intervention that would fit PTO's rules. Like Susan Love, Ravicher helped the outsider activists navigate a highly technical domain in order to make their voices heard.

FTCR also tried to demonstrate its own understanding of the legal and scientific dimensions of the case and of the patent policy domain by discussing the novelty criterion for patentability through multiple media outlets. Although it primarily worried about the impact of the hESC patents on research and health care, FTCR made a different argument in its press statements, op-eds, and blog posts. In these places, it repeated the argument from the re-examination request, stating that WARF did not deserve a patent because hESCs were not new: other scientists had already found, isolated, and propagated them (Gallagher, 2007; Simpson, 2007.) This approach allowed FTCR to demonstrate that it understood how the patent system worked — that the PTO rewarded inventions that were new — and that it supported these goals. Its personnel hoped that by demonstrating their expertise they would gain political standing (FTCR representative, personal interview, 2009.)

Both breast cancer and patent challengers tried to demonstrate to insiders that they understood the language, concepts, and rules of their respective domains. Therefore, they deserved to participate. We can see, however, that while both groups took advantage of sympathetic insiders and deployed established expertise themselves, the level of formality of their strategies differed.

Introducing new kinds of facts

In addition to deploying established expertise, breast cancer activists also tried to influence research policy by introducing new kinds of evidence about environmental causation. This epidemiological evidence had not traditionally been valued in the biomedical research policy domain; the NIH and other federal agencies had traditionally underfunded this kind of research into the environmental causation of breast cancer, suggesting that it was 'squishy', and that they 'don't believe it works anyway' (Brown *et al.*, 2006). Activists fought against these presumptions by arguing that epidemiological facts were relevant and that the government needed to fund this research.

Activists' efforts began in 1993 when, angered that a New York state study on breast cancer had ignored environmental etiology, local advocacy groups forced the NIH to initiate an epidemiological study to study these issues on Long Island (Brenner, 2000). Soon afterwards, California-based Breast

Cancer Action (BCA) pressured the NCI to examine the relatively high breast cancer rates in the San Francisco Bay Area. By 1996, BCA had issued consensus points demanding the NCI fund more epidemiological research to study the relationship between the environment (particularly environmental toxins) and breast cancer incidence. It stated, for example:

It is essential that the National Cancer Institute recognizes that genes do not function in a vacuum. Identifying the factors that affect penetrance and expression of mutations is critical to finding effective means of reducing an individual's risk. Such research may have widespread implications for sporadic as well as hereditary breast cancers and will potentially benefit everyone, as everyone is at risk. (Brenner, 1996)

Responding to the NCI's traditional focus on genetic causation and research efforts at the cellular and molecular levels, BCA asked: if we really want to know how breast cancer works, and what causes it, shouldn't we more seriously consider environmental causation and the answers that epidemiological research could provide?

Over the next decade, as breast cancer activists achieved increased research funding for the disease (Stabiner, 1998), their call for environmental research intensified. In 1998, NBCC convened an 'Environmental Summit' among government officials, scientists, and activists, in order 'to begin an ongoing dialogue about incorporating environmental issues' into breast cancer research policy (NBCC, 2004). Finally, in 2002, the NIH agreed to consider increasing its focus on the links between breast cancer incidence and the environment. Initial fact-finding meetings and workshops, not surprisingly, included prominent involvement from breast cancer advocates (the president of NBCC served as co-chair at one of these meetings, for example) (NBCC, 2004). Later that year, the NIH established Breast Cancer Environmental Research Centers, which it promotes as collaborative efforts between 'scientists, clinicians, and breast cancer advocates' (BCERC, 2009). As breast cancer activists created a space for research into environmental etiology, they established their own standing as participants in the domain.

Challengers to life-form patents tried to insert themselves into the patent policy domain by using a similar strategy. In their first intervention, the *Chakrabarty* case, they argued that patent policy could not be based simply on prior case law, scientific feasibility, and national economic competitiveness. Policy-makers had to consider environmental, health, and global economic evidence in order to properly understand the implications of allowing patents on life forms. For example, activists argued that the allowance of plant patents since early in the 20th century provided an important test case. (Specific 'plant' patents had been allowed since 1930,

but the issue at stake in the *Chakrabarty* case was whether the Supreme Court should allow 'utility' patents, which generally open up broader rights for the inventor, on all living organisms — including plants) (Fowler, 2000).

Citing economic reports by a Presidential Commission on patents and conclusions drawn by the respected National Academy of Sciences,⁴ activists suggested that plant patents had resulted in corporate consolidation of the agricultural industry, which had negatively affected agriculture and the world food supply by:

1. Eliminating plant varieties;
2. Creating monocultures which could be completely eliminated by one pest or disease; and
3. Disadvantaging small farmers (People's Business Commission, 1979).

If the Supreme Court allowed utility patents on all living organisms, they argued, such effects would likely be magnified. As they made these arguments, challengers simultaneously introduced new types of evidence and established their mastery over them.

Patent challengers justified the inclusion of new types of evidence by arguing that it would allow a comprehensive assessment of the implications of life-form patents and that it was important for the maintenance of democratic ideals. During Congressional hearings regarding animal patentability held in 1988, a member of the Wisconsin Farm Alliance advocated attention to the environmental and health implications of the practice by remarking,

We believe that the people speaking for extending patent protection to genetically altered animals are too impatient to wait for the people to make up their minds about these issues. Allowing patent protection at this time will sever the connection between research and the public interest. (US House of Representatives, 1988: 324)

In order for patent policy (and the research enterprise more broadly) to truly operate in the public interest, he argued, it had to be comprehensively and methodically considered using multiple forms of evidence.

Although patent challengers made broader claims than breast cancer activists about how the inclusion of different kinds of evidence would benefit the 'public interest', the strategies of these groups were remarkably similar. Each tried to incorporate evidence that was new to that policy domain, but each of these types was already accepted elsewhere. This connection could provide activists with additional momentum; they were not questioning the evidentiary basis of these domains independently, but rather with the help of experts who had established themselves elsewhere and were likely happy to expand their reach into another policy domain.

Introducing new policy-making logics

Breast cancer and life-form patent activists also suggested new policy-making logics that would change the evaluation of both old and new types of evidence. The two breast cancer groups, NBCC and BCA, proposed the shift in the late 1990s, after the two organizations had achieved some success. They both challenged the linear model (Sarewitz, 1996) of scientific and technological development, the logic that has driven US research funding policy since World War II: it suggests that more support of science will lead to social benefit. According to this logic, both broad decisions about what kinds of research to fund, and individual decisions about which proposals to fund, are made on the basis of scientific merit. Well-established researchers serve as peer reviewers, judging each proposal by evaluating the description of the project and the previous successes of the investigators.

BCA's alternative, for example, placed much greater value on research programs that offered clear benefits to health. In particular, it suggested, 'More funding is not the answer; properly focusing the available funding is' (Brenner, 1996). It suggested an iterative approach, starting with a detailed accounting of where previous government investments had led, and how they had affected health outcomes, in order to identify what had been successful and how best to spend future monies. This logic required the introduction of new evidence and experts. Because of the explicit attention to improving the lives of breast cancer sufferers, a larger role would be created for knowledge about the social, environmental, and economic dimensions of the disease. This might include a more serious role for patients (or, at least, their activist representatives), who could discuss health benefits in the context of their disease experiences. The alternative logic also required a new way of valuing evidence and expertise. Traditional indicators of a researcher's success — her previous grants, successful graduate students, and publications in highly ranked journals — would become less important than her record of contributions to breast cancer amelioration.

Life-form patent activists also challenged the linear model that guides that domain. Here, the traditional logic views patents as the means to achieve increased innovation, which leads to a stronger economy and ultimately an improved society (Hilgartner, 2009). Efforts by policy-makers and insiders to reform the system focus primarily on how it can stimulate innovation more efficiently and effectively (Jaffe and Lerner, 2004).

Activists opposing patents on life forms, however, questioned the idea that patents always generate social benefit through innovation; certain kinds of inventions, they argued, might be economically beneficial but would be ethically problematic and socially detrimental if they were commodified and subject to market forces. In place of the linear

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approach, challengers offered an alternative logic that would require decision-makers to balance ethical and social harms and benefits. They defended this logic by suggesting that policy-makers had stepped into other domains in which economic benefits conflicted with moral responsibilities to living organisms. In the Congressional hearings that focused on the patentability of animals, the leader of the National Council of Churches explained,

This background has led to legislation such as endangered species laws, animal welfare laws, laws regarding environmental quality. (US House of Representatives, 1988: 394)

This alternative logic required decision-makers not only to consider new kinds of evidence and expertise about the environment, health, and ethics, but also to develop an evaluation mechanism that would balance these different kinds of knowledge with traditional evidence of scientific novelty, legal precedent, and economic utility. Not surprisingly, it also created new roles within the patent policy domain for the activists who possessed these types of expertise.

An interesting similarity appears when we analyze how breast cancer and patent challengers offered alternative logics to their respective policy domains. Both types of challengers questioned the linear model of scientific and technological development, and proposed more iterative processes that did not take for granted the social benefits of innovation.

Attacking bureaucratic rules

Finally, breast cancer and life-form patent activists tried to break expertise barriers by challenging the rules of the most highly technical spaces in their respective domains: bureaucracies. Soon after their initial successes in increasing funding for breast cancer research in the early 1990s, activists began to question the rules for participating in the grant-funding process (Andjeski *et al.*, 2002; McCormick *et al.*, 2004). Research-funding bureaucracies had developed grant review based on the idea that science-based decisions are egalitarian and transparent, and therefore in the public interest. Activists challenged this presumption by suggesting

that decision-making based on scientific evidence and expertise also meant decision-making on the basis of *scientific* priorities. This should, they argued, be distinguished from the priorities of *patients*. Activists argued that as interested users and disease sufferers (with technical expertise gained through Project LEAD), they were at least as, if not more, appropriate reviewers of research proposals. Fran Visco, the president of NBCC, noted,

They [scientists] think we're going to be there to scream. They think we're going to be there to bare our breasts. But what we want is to make sure the money we fought so hard for isn't wasted ... What we want is answers. (Erikson, 1995)

Activists wanted to ensure that the processes for funding breast cancer research were related to the amelioration of breast cancer, which they believed to be the public's goal. They also introduced the idea that the grant-making process might look different if it reflected the priorities of patients as well as scientists. Visco stated elsewhere:

Money alone is not enough to end the breast cancer epidemic. We need to bring the perspective of the patient, the breast cancer activist, to the table where breast cancer research decisions are being made. (NBCC, 1998)

Activists' demands to participate in grant review forced scientists and government officials to consider the norms and rules of their decision-making processes. Were they arbitrary? Were they defensible? What would a grant-making process based on the priorities of both groups look like? Could scientists and government officials continue to claim that they were working in the public interest if they refused to allow entry to the users of biomedical S&T? Eventually, the NCI (and the Department of Defense, which had begun to fund breast cancer research as well) decided to permit activists to participate in peer-review panels (Dickersin *et al.*, 2001).

Life-form patent activists have also attacked the bureaucracy in charge of patent decisions, the PTO. However, rather than questioning the rules of participation as breast cancer activists did, these activists adopted a confrontational approach. They tried to expose the values underlying the PTO's supposedly objective rules for examining and granting patents and argue that they were against the public interest. Jeremy Rifkin and Stuart Newman, a developmental biologist from New York Medical College affiliated with the Council for Responsible Genetics (a watchdog group focused on biotechnologies) launched one of the first challenges, by applying for a patent covering a chimeric embryo comprised of both human and non-human (animal) cells (Newman, 1997). They wanted the public to see that PTO's approach privileged certain values over others

(e.g. it emphasized more and stronger patents as a means of achieving economic growth), which could lead to patents on shocking inventions (Newman, 2007.) Patents on such inventions, they argued, would encourage their development and commercialization. Newman and Rifkin suggested that if the public really understood the values implicit in the PTO's patentability rules, they would pressure the PTO to re-evaluate its processes with different values in mind. Striving toward this goal, they immediately leaked news of their application to the media (Newman, 2007; McKenzie, 1998; Weiss, 1998; Zwerdling, 1998).

PTO officials responded to the invention and the accompanying publicity with anger at this interference in their expert space (Dowie, 2004). While Newman and Rifkin argued that as citizens, they had as much right as anyone else to access and engage the patent system, bureaucrats (and traditional stakeholders) re-emphasized the PTO's separation from the political arena. These people, and these arguments, just simply didn't belong. They refused to engage Newman and Rifkin in a discussion about the values embedded in the PTO's approach. Instead, the PTO rejected the patent on multiple grounds, including that it was insufficiently described and lacked an inventive step over previous technologies (Crouch, 1999.) In 2005, Newman and Rifkin finally abandoned their application. Although the PTO and the patent policy domain still maintain a strong expertise barrier, the chimera application has inspired other similar activist challenges to the PTO's decision-making processes (see, for example: American Anti-Vivisection Society *et al.*, 2007; Public Patent Foundation, 2006).

Discussion

I have argued that as activists challenge policy domains related to S&T, they contend with an 'expertise barrier', which tends to block those lacking the requisite specialized knowledge from full participation. The presence of an expertise barrier raises a series of questions for activists. Should they attack the barrier and try to gain entry into the domain, or should they simply give up? To what extent do they need to break the barrier in order to influence policy-making? If they choose to attack, what strategies will work best to break the barrier? In this article, I have argued that when activists choose to confront an expertise barrier, their major strategies fall into four major types: deploying established expertise, introducing new kinds of facts, introducing new policy-making logics, and attacking bureaucratic processes. Putting these advocacy strategies into a framework allows us not only to organize existing and future analyses, but also to encourage comparison and open up new lines of inquiry.

Table 1 summarizes the examples of breast cancer and life-form patent activism to illustrate the use of

this framework. While both sets of activists used all four strategies, they sometimes employed them differently, and they enjoyed different levels of success.

These examples suggest further questions for research. Do challenges typically deploy all four strategies as they did in the breast cancer and life-form patent cases? Although the activists described in this article used all four strategies, much of the scholarship on activism in S&T policy domains focuses on the first two strategies — deploying established expertise and introducing new kinds of facts. If we look back at these cases, will we see that other activists use the other two strategies as well, or are certain strategies simply more prevalent than others? Also, can we deduce any more detailed trends in the tactical choices that activists make? When breast cancer and patent activists challenged the dominant policy-making logics of their respective domains, they focused on the linear model of scientific and technological development and proposed more iterative processes that did not take for granted the social benefits of innovation. Is the challenge to the linear model common among most activists trying to introduce new policy-making logics, or was this approach chosen because of the specific domains that breast cancer and patent activists were targeting?

This framework can also help us begin to develop hypotheses about the conditions that lead to advocacy success in breaking expertise barriers. In this regard, breast cancer activists have been somewhat more successful than challengers to the patent system. Not only have they achieved an enormous increase in government funding for research into the disease (Stabiner, 1998), but they have also influenced the distribution of these funds (McCormick *et al.*, 2004). Breast cancer activists now sit on grant review committees and advisory boards that determine broad strategies for research funding. By contrast, while challengers of patents on life forms have successfully generated some scholarly, media, and occasionally policy discussion (Cardozo Law School Symposium, 2006), their concerns are still considered peripheral and there has been little policy

change. They are still seen as outsiders, without legitimate standing in the domain. What, then, might account for their relative success and failure?

The possible explanations are numerous, and would benefit from the consideration of additional empirical material. But the analysis presented above suggests several lines of investigation.

First, we might consider the specific tactics chosen. While both groups tried to deploy established expertise, for example, breast cancer activists created more formal mechanisms to develop and deploy their expertise than their counterparts in the life-form patent case. NBCC created a certification program, which involved scientists and physicians as educators, but patent activists adopted a more *ad hoc* approach.

Also, while both breast cancer and patent activists attacked rules for bureaucratic decision-making, they positioned themselves quite differently. Breast cancer activists sought to become equal participants in the grant review process, arguing that their involvement was an important step towards better decisions. Patent challengers adopted a more confrontational stance, trying to open the patent examination process up to public scrutiny in order to demonstrate its systemic flaws. They sought to create a spectacle, which they hoped would draw broader scrutiny and, eventually, change the PTO's rules.

Did these tactical differences influence the likelihood of their success? In order to answer such a question, we would need to observe other advocacy successes and failures in penetrating expertise barriers, with particular attention to precisely how they implement lines of attack (e.g. how they deploy established expertise and challenge bureaucratic rules.)

Second, we might consider whether the order or pace of employing these types of challenges follows any important patterns. While breast cancer activists introduced new policy-making logics only after they had engaged in the other three strategies, patent activists attempted this strategy early in their mobilization. Did patent activists diminish their chances of

Table 1. Comparing activists' attempts to break the expertise barrier

| | Breast cancer activists | Patent activists |
|--------------------------------------|---|--|
| Deploying established expertise | Use translational figures Set up a certification program | Use translational figures Write op-eds, public statements |
| Introducing new facts | Deploy environmental and epidemiological evidence | Deploy ecological, global economic, health evidence |
| Introducing new policy-making logics | Argue that research funding should be driven by prospect of health benefits | Argue that patents should not be granted on ethically problematic technologies |
| Attacking bureaucratic rules | Challenge the rules of participation for grant review | Assert that patentability rules are based on values that are against the public interest |

success by challenging the dominant logic so early? Is a particular progression of strategies correlated with greater success?

Third, theorists of social movements have described how activists must have access to resources — financial, organizational, rhetorical, and cultural — in order to mobilize and be successful (McAdam *et al.*, 1996). Do the same rules apply when dealing with S&T policy domains that have particularly high expertise barriers?

Finally, perhaps the relative success and failure of these strategies can be understood through further analysis of the characteristics of the domains. Have other advocacy groups trying to break the expertise barriers in the research and patent policy domains met the same fates? In other words, to what extent can the relative success and failure of the activists discussed here be explained by the types of knowledge privileged in each domain, or by the characteristics of the outside challengers? What makes an expertise barrier particularly strong or weak?

This framework may also be useful for analyzing advocacy strategy in policy domains not conventionally seen as involving S&T. The recent economic crisis reminds us that policy domains that deal with financial markets, for example, also have rather strong expertise barriers. Do these barriers play the same role here as they do in S&T policy domains? Do activists use similar strategies to overcome them? To what extent is the framework developed here generalizable? While this framework has focused on advocacy in domains engaged in S&T policy-making, it can help to initiate a conversation about the politics of knowledge in a broader set of policy domains — and the implications of these politics for the dynamics of public engagement, the scope of debate, and the meaning of democratic policy-making.

Notes

1. I define 'life form' patents as those that cover living organisms or their parts, and methods of making them. This includes product and process patents on genes, germ and stem cells, and genetically engineered microorganisms, plants, and animals, among other things.
2. Some analysts may argue that many policy domains could, at least partially, fit into this category; aspects of economic policy, for example, include highly technical decisions. While the areas I focus on here are those that are likely to be seen by actors and analysts alike as having high expertise barriers, I recognize that it could be possible to include in the analysis cases that may not explicitly involve complex discussions about S&T but are still highly technical.
3. I have conducted qualitative research on both breast cancer and patent activism. This research has involved archival research and document analysis, almost 200 interviews with members of activist groups, government officials, and stakeholders operating in these policy domains, and ethnographic observation of both advocacy group activity and government decision-making processes.
4. For example, the coalition cited: Committee on Genetic Vulnerability of Major Crops, National Research Council 1972. *Genetic Vulnerability of Major Crops*. Washington, DC: NAS Press; Committee on Germplasm Resources 1978. *Conservation of Germplasm Resources*. Washington, DC: NAS Press;

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